

## **MEMORANDUM**

**TO:** Interested Persons

**FROM:** Don Sloma, Staff Coordinator

**DATE:** October 24, 1996

**RE:** Issue Overview for End-of-Life Care Work Session --- November 15

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### **Introduction --- Interim Work Group on End of Life Issues**

In April 1996, Chairman Quigley appointed a four member Interim Work Group on End of Life Issues. Its co-chairs are Senators John Moyer and Pat Thibaudeau. Its member are Senators Alex Deccio and Rosa Franklin. At the Work Group's direction, staff compiled an overview of a range of end of life issues including descriptions of

- existing medical and social service treatment standards and practices,
- relevant elements of existing systems of moral guidance,
- financing and payment arrangements, and
- legal and constitutional issues.

Research involved a review of the professional literature, contacts with relevant national clearinghouses, a review of judicial literature, and key informant interviews with some sixty-five experts from medicine, nursing, insurance, public health, medical education, long term care, hospice, home health, community action organizations, bioethics, major religions, the legal profession and health care purchasing.<sup>1</sup>

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<sup>1</sup>For a summary of the Interim Work Group's study process and objectives to date, see the Senate Health and Long Term Care Committee's homepage at <http://www.leg.wa.gov/www/senate/scs/hea/commhea.htm>.

The staff review identified a widely documented set of concerns regarding many aspects of care at the end of life. It also identified a number of efforts underway both within our state and across the nation to address these concerns. It seems the United States Supreme Court's consideration and recent acceptance of two appellate court cases<sup>2</sup> on physician assisted suicide for review this term has spurred a number of significant health policy development groups to conduct critical examinations of the medical care system and of related professions relative to care at the end of life.<sup>3</sup>

After reviewing the information compiled by staff, the Interim Work Group chose to begin a public dialogue by seeking testimony on a limited number of issues which seemed to be at the center of many of the study and remediation activities now underway. These issues were chosen for discussion at the Work Group's first public work session on November 15. They are 1) existing professional standards and practices, 2) physician training and 3) public education about care at the end of life. This memo frames these subjects<sup>4</sup>.

### **Background --- The Circumstances of Death in Washington**

While estimates of requests for assisted suicide at the end of life vary widely,<sup>5</sup> there is no doubt that such requests have spurred many to ask why death has come to be so prolonged, painful and lonely in a society with such an advanced system of medical care.

Tables 1 and 2 show 1994 Washington deaths by location and major cause. Despite the fact that the majority of the approximately 40,000 deaths in our state each year are from long term illnesses

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<sup>2</sup>The appellate decisions are *Compassion in Dying v. State of Washington (Compassion II)*, 49 F.3d 586 (9th Cir. 1995); *Compassion in Dying v. State of Washington (Compassion III)*, 79 F.3d 390 (9th Cir. 1996) and *Quill v. Vacco*, (Quill) 80 F.3d 716 (2nd Cir. 1996).

<sup>3</sup>The American Medical Association, the National Academy of Sciences within the Institute of Medicine, the Washington State Medical Association and many other professional, religious and philanthropic groups have convened formal studies of these subjects in recent years. At least the states of New York, Michigan, and New Jersey have convened broad based, formal commissions. Also, the federal Agency for Health Care Policy and Research, the private Hastings Center, the Soros Foundation and many other academic researchers and other public and private groups have been active.

<sup>4</sup>The Committee Work Group directed staff to assemble several panels to discuss these issues at a public session. The preliminary agenda for the work session is Attachment 1.

<sup>5</sup>Attachment 2 is a report of The Council on Scientific Affairs of the American Medical Association which cites various studies placing suicidal ideation at 3% to 20% among cancer patients. Back et. al. reported that 26% of Washington physicians responding to their 1995 survey received one or more explicit requests for physician aid in dying. Ezekiel et al report more than half of the oncologists in their survey had received requests for assistance with suicide or euthanasia.

where death is the predictable end point, a distinct *minority* of deaths occur in hospice settings (10% to 20%).<sup>6</sup>

Indications are that for many others with longer term illnesses, death occurs under circumstances where pain may not be adequately treated.<sup>7</sup> Patients and family may not be adequately informed or involved in the dying process. Spiritual needs may not be adequately addressed, and choices regarding the manner and the timing of death may not be adequately respected. Death may occur after the family or their insurer has incurred great expense for treatments that may not only have been unwanted and ineffective, but also may have prolonged the pain and suffering which preceded the final, inevitable outcome.<sup>8</sup>

Experts in death and dying generally define a "good death" as involving a patient's control over the course of their treatment, adequate pain management, adequate support in activities of daily living, adequate social and psychological support and treatment (especially for depression), spiritual support and counseling, and adequate social and spiritual support for friends and family members during the time surrounding death.<sup>9</sup>

To improve care at the end of life, physicians and others have developed a series of professional practice standards and guidelines. Many are comprised in what is commonly referred to as "palliative care", or are now delivered as long term care. Some involve known medical treatments.

However, there is troubling evidence that at least so far, these guidelines and practice standards may serve more as goals than as descriptors of practice.<sup>10</sup>

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<sup>6</sup> While predicting the exact date of death may be difficult in many of these cases, the time course of the diseases responsible for the majority of Washington deaths is ordinarily measured in months or years from onset to death. Despite this relatively long time frame, best estimates from our state Department of Health are that no more than 20% of deaths occur in hospice settings or under other circumstances designed specifically to provide aid and support to the dying and their family members (Precise statistics on hospice deaths are not collected by the state at this time.).

<sup>7</sup>The New York State Task Force on Life and the Law (page 43) reported on several studies conducted within the past 5 years which concluded that "...only 25 to 70% of post operative pain, and 20 to 60% of cancer pain is treated adequately. In one study of 897 physicians who care for cancer patients, 86% reported that most patients with cancer are under medicated.... In another study of 687 physicians and 759 nurses, 81% agreed with the statement, 'The most common form of narcotic abuse in the care of the dying is under treatment of pain.'

<sup>8</sup>See Nuland, 1993 and Callahan, 1993 for discussions of the dying process in America. Also see Attachment 2 for a summary of the epidemiology of dying including problems with the use of advance directives.

<sup>9</sup>See O'Neil, 1983 for a discussion of the elements of a good death. Sharp, 1995 has a typical description of the elements of quality care in hospice, or Bylock, 1996.

<sup>10</sup>See the Attachment 2 or the New York or Michigan Commission reports for discussions of these points.

The reasons for this are complex, and may be deeply rooted in our medical care system, in our culture's view of life and death, and in the roles of individuals, spiritual belief systems, society and government.

### **Current Standards of Care and Professional Practice**

For physicians and others in the medical system, delivering care at the end of life presents new and difficult challenges. “Physicians discover that they must confront the limits of life. But as medical professionals, they can adopt a new and satisfying role that supplants that of medical interventionist.”<sup>11</sup>

The term “palliative care” is used to describe the series of medical, social, psychological, spiritual and communication skills and interventions which form the basis of efforts to improve care from the inception of a terminal disease until death occurs. Palliative care seems to have developed primarily out of care for cancer patients, and includes significant contributions from the fields of pain management, nursing, psychiatry, psychology, internal medicine, spiritual counseling and other disciplines. Palliative care has strong roots in hospice, an integrated approach to providing care and comfort to those who are dying.

The hospice movement, which emerged in the United Kingdom in the 1960s, moved to the United States by the early 1970s, and is now seen by some as the “... cradle for the evolution and maturation of palliative care.”<sup>12</sup>

It has given rise to a series of widely supported professional guidelines which are now available to deal with most end of life care issues. The federal Agency for Health Care Policy and Research, the American Academy of Hospice Physicians, the American Nurses Association (for hospice nurses), the American Board of Internal Medicine, Medicare and other organizations all have published guidelines.

At least two national groups, the federal Agency for Health Care Policy and Research and the American Pain Society, have published separate guidelines for pain management in recent years.<sup>13</sup> In Washington state, the Department of Health published pain management guidelines earlier this year.<sup>14</sup>

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<sup>11</sup>Washington State Medical Association, 1996, page 17.

<sup>12</sup>Bylock, 1996.

<sup>13</sup>See JAMA, December 20, 1995: Vol.274: 1874-1879 for a discussion of the American Pain Society guidelines development and testing.

<sup>14</sup>Miyahara, Bruce, “Guidelines for Management of Pain”, Washington State Department of Health, February, 6, 1996.

Despite the proliferation of guidelines, significant documentation exists that many health care practitioners may not be aware of, or may not be comfortable in applying them. Problems cited are many including, poor communication between patients, family members and physicians, poor communication among health care providers, difficulty determining the course of an illness and identifying the point at which it is no longer curable, patient or family denial, reluctance to foster addiction to pain medication, ignorance of recent advances in pain management or other palliative care interventions and more.<sup>15</sup>

Among many suggestions which have been advanced to address these concerns are:

1. Facilitate a cultural change in Medicine on death and dying, recognizing and strengthening the role of Medicine not only in curing illness, but also in aiding the dying process in terminal cases without necessarily hastening it,
2. Encourage physicians to approach patients earlier in treatment regarding end-of-life care options and philosophies,
3. Provide a list of diagnoses as guidelines to assist hospitals, nursing homes and other health care facilities in determining a broader group of candidates for palliative care or hospice care,
4. Improve the definition of "life support" in DNR orders and Advance Directives, and/or
5. Develop a pilot project to demonstrate the benefits of more comprehensive adherence to new professional standards regarding earlier referral to palliative care, more completely integrated curative and palliative care, better pain management, and more comprehensive social, psychological and spiritual counseling of terminal patients and their loved ones.

### **Physician Training<sup>16</sup>**

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<sup>15</sup>See Attachment 2 for a summary discussion and references. Or see The SUPPORT principal investigators, *JAMA*.1995;274:1591-1598. WSMA, 1996 observations about the impact of 1996 Washington State Pain Management Guidelines are "...that approval has not so far resulted in detectible changes in physicians' prescribing behavior. Fear of regulatory scrutiny, as well as public and medical community bias against the use of opiates still remain major impediments to effective palliative care."

<sup>16</sup>The focus in this memo on physician education reflects the work group's desire to begin its inquiry within a manageable, limited scope. It does not reflect any conclusion about the need for attention to the training of other health professionals in end of life issues. Nor does it reflect a lack of interest in the efforts currently underway within the professions of nursing, social work, psychiatry, psychology, bioethics or other specialties.

Despite the fact that standards for pain management and professional practice at the end of life now exist, many physicians are not aware of, or do not practice in ways that incorporate them.<sup>17</sup> And there is evidence that training nurses and allied health professionals to intervene in these situations may not be sufficient.<sup>18</sup>

One reason frequently cited for poor adherence to standards is a lack of training for physicians.<sup>19</sup>

In our state, the University of Washington reports that at least one 10 week class from their Medical History and Ethics Department is devoted to socio-psychological and ethical issues in end of life care. In addition, a required two day seminar is held at the end of the second year of medical school during which end of life clinical issues and related subjects are discussed. Other, more specialized classes are offered to graduates in residence. Finally, end of life issues are discussed in many other classes, and as the situation warrants in clinical instruction.<sup>20</sup>

Dr. Thomas McCormick, D. Min., Senior Lecturer in the Department of Medical History and Ethics at the University of Washington is currently leading a five year, privately funded effort with the non-profit organization Choice in Dying to improve medical education in care for the dying at the University of Washington School of Medicine. Funded by the Greenwall Foundation, the project will assess existing efforts, develop several teaching models and field test them. According to Dr. McCormick, “Despite some educational improvements, no consensus has been reached within medicine regarding how to teach medical students about care of the dying. Medical school education must help future physicians understand that the comfort care needed by those who cannot be cured is as important as the curing that most medical schools teach.”<sup>21</sup>

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<sup>17</sup>The 1996 Washington State Medical Association Executive Committee Report “G” notes, “... the federal Agency for Health Care Policy and Research guidelines for managing acute pain and cancer pain, issued in March 1994, have largely gone unheeded, and clinical practice has not been much affected. Too few physicians attend the grand rounds or pharmaceutical company sponsored courses where education on end-of-life and palliative care issues takes place.” (page 19). Also see Back et al, *JAMA*, 1996.

<sup>18</sup>See The SUPPORT Principal Investigators, *JAMA*, 1995.

<sup>19</sup>In 1993, the American Medical Association Council on Medical Education reported that only five of 126 medical schools had separate required courses on death and dying, although 117 include some information as part of other required courses. Only 26% of residency programs offered instruction on end of life medico-legal issues. In 1995, the AMA Board of Trustees (Dickey, 1995) recommended among many other actions to improve care at the end of life, several steps to promote integration of end of life care issues with both clinical and ethical curricula, including pain management, hospice and more. Also see WSMA, 1996, page 17, and their recommendation (page 33) to “... work with the leadership of the University of Washington School of Medicine to inventory current approaches to student and physician training in end of life care, and based on the findings, explore ways to substantially improve this training and care...”

<sup>20</sup>Interview with Dr. Thomas McCormick, D. Min., Department of Medical History and Ethics, University of Washington, School of Medicine.

<sup>21</sup>University of Washington, 1995.

Among the suggestions to further advance medical education in end of life issues are:

1. Educate pediatricians on talking to dying children and their families, and providing appropriate pain management for pediatric patients.
2. Educate physicians on pain management and palliative care earlier in their training, including particular attention to education on the availability of guidelines for the use of opiates in pain management for the terminally ill.
3. Expand medical school education to include skills development and clinical competence, in part by developing a palliative care research and training center at some institution of higher education or elsewhere.
4. Educate physicians on liability issues surrounding honoring directives and DNR orders.

### **Public Education**

Many have suggested that broadly shared, public attitudes about death, and the resultant unrestrained demands made of the medical care system for heroic interventions are significant contributors to the delayed receipt of palliative care.<sup>22</sup> Many groups in our state, including local hospice agencies, the Hemlock Society, the American Association of Retired Persons, the American Cancer Society, the Washington State Cancer Pain Initiative, Cancer Information Services, Washington State Hospice Organization, Compassion in Dying, some health insurers, the state medical association and others have attempted to provide public education to increase awareness and begin changing attitudes about death and dying.

In addition, it has been noted that the movement for living wills and advance directives has helped to increase awareness of these issues among those entering health care facilities, if not the course of clinical decision making.<sup>23</sup>

Now our state medical association, and an ad hoc group of health professionals concerned about end of life care, have each suggested that improvements in end of life care might be made by even

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<sup>22</sup>Various observations about our culture's view of death and dying and the role these views play in end of life care decision making are contained in books and articles on these subjects. See Nuland, 1993, Callahan, 1993 or Sonnenblick, 1993 for a few examples. One interesting compilation of our cultural images of death can be found on the Internet at [www.trinity.edu/~mkearl/death-4.html#us](http://www.trinity.edu/~mkearl/death-4.html#us).

<sup>23</sup>Teno, 1994.

more aggressive efforts at changing public attitudes and knowledge about death, dying and palliative care.<sup>24</sup>

At least one national philanthropic organization concerned about end of life issues has directed a portion of its giving to “The design, implementation, evaluation, and dissemination of educational programs for the public about death and dying.”<sup>25</sup>

The suggestions that more be done to educate the public about death, dying and end of life care issues, include:

1. Expand and improve community or "consumer" education on a "good death" and end-of-life decision-making through the media, health education classes and public forums.
2. Include education on death and dying in K-12 education.
3. Improve public education surrounding advance directives, and the differences between durable powers of attorney, directives, and do not resuscitate orders.

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#### SOURCES:

Agency for Health Care Policy and Research, Management of Cancer Pain, U.S. Department of Health and Human Services; March 1994.

American Pain Society Quality of Care Committee, “Quality Improvement Guidelines for the Treatment of Acute Pain and Cancer Pain,” *Journal of the American Medical Association*, December 20, 1995; 274:1874-1879.

Back, Anthony L. MD; Wallace, Jeffrey, I. MD, MPH; Sparks, Helene E. MPH; “Physician Assisted Suicide and Euthanasia”, *Journal of the American Medical Association*, March 27, 1996; 275: 919-925.

Bylock, Ira, M.D., President, Academy of Hospice Physicians, in Written Testimony to the National Academy of Sciences, Institute of Medicine, Committee on Care at the End of Life; May 20, 1996.

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<sup>24</sup>WSMA, 1996, page 22. Page 34 suggests a jointly sponsored conference on community education strategies as well as various WSMA community education activities. An ad hoc panel of Washington State health professionals also recommends various community education activities. (See Panel, 1996.)

<sup>25</sup>The Project on Death in America, funded by the Open Society Institute and George Soros has funded no less than eight projects which promote public education and dialogue around end of life issues.



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- Dickey, Nancy, MD, “Report to the Board of Trustees on Quality Care at the End of Life”, *American Medical Association, Report 48-I-95*.
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- Stephenson, Jr. Hugh E., MD, “Report of the Council on Medical Education - Developing a Medical Education Curriculum for End of Life Care”, American Medical Association CME Report 4-I-94.
- The SUPPORT Principal Investigators, “A Controlled Trial to Improve Care For Seriously Ill Hospitalized Patients”, *Journal of the American Medical Association*, November 22, 1995; 274:1591-1599.

University of Washington, “School of Medicine one of 10 in National Effort to Improve Training for Care of Dying”, November 9, 1995;13:7.

Teno, JM, Lynn J, Phillips, RS, et al. “Do Formal Advance Directives Affect Resuscitation Decisions and the Use of Resources for Seriously Ill Patients?”, *Journal of Clinical Ethics*, 1994;5:23-30.

Washington State Medical Association, Report “G” of the Executive Committee on End of Life Issues, 1996.

Attachments:

- I Preliminary Agenda: November 15, 1996 Work Session
- II “Good Care of the Dying Patient”, *JAMA*; 1996;275:474-478.